IBD programme

Transition to the IBD Registry – Frequently asked questions (March 2016)

Getting started / Registration

Q. What should I be doing at the moment?

A. Continuing to enter your data to the biological therapies audit web tool and returning your registration form.

Q. Will I need to continue entering data to the biological therapies web tool once I am set up to use the IBD Registry?

A. No. Once you are ready to begin entering your data through any IBD Registry compliant system, you can stop entering your data to the biological therapies audit web tool.

Q.. What is the definition of IBD Registry compliant?

Any system that has been approved by the IBD Registry as holding the core IBD Registry dataset and able to export this for analysis and linkage.

A.

Q. Should we register our adult and paediatric services together, or separately?

A. This is entirely your decision. If you do register together, users will be able to see the details of all of the patients entered. You can still separate the adult and paediatric patients using a filter, if you wish. Alternatively, we can set you up with separate accounts for your adult and paediatric services.

Q. If we register as a Trust/Health Board, can we still get a hospital level breakdown?

A. You can register in whichever way suits you best. If you register for a Trust/ Health Board-wide account, you will be able to see all of the data entered and may need to add a hospital code to be able to distinguish between patients that were treated at individual hospitals. You could alternatively use the 'responsible clinician' field to do this if clinicians work at defined sites only.

Q. What data should I capture initially?

A. You can use the IBD Registry in many ways. To be classed as having 'participated' for the purpose of your quality account (or similar) reporting, you will need to have met the following criteria:

- Exported your data from the biological therapies audit web tool
- Begun to collect data using an IBD Registry compliant IT system
- Entered data for the 6 performance / quality indicators, for all of your patients that have been newly started on biological therapies

Q. What are the 6 performance / quality indicators?

A. For all patients newly started on a biological therapy, performance will be reported on the following items:

1. Whether pre-treatment screening was undertaken
2. Whether there was a post-induction review (at 3 months post initiation)
3. Whether a formal assessment of disease activity was undertaken at this time

4. Whether there was a 12 month review
5. Whether a formal assessment of disease activity was undertaken at this time
6. Whether there is a record of consent having been discussed with all patients

General

Q. What information will be in the starter pack?

A. Once you are registered with us, we will send you out a starter pack. This pack will guide you through all of the relevant steps to get up and running with your data collection. This pack will also contain information about the performance / quality indicators that will be reported on during the year.

Q. Will you provide us with printable data collection tools?

A. Initially we will make a printable data collection tool available so that you can collect the relevant data the performance/ quality indicators. However it is intended that in time data collection for the IBD Registry will take place in real time, during the clinical consultation.

Q. What is next for the biological therapies audit?

A. For now, the biological therapies audit web tool remains open for you to collect information on your patients. In the next few months you will need to export your data and move to an IBD Registry compliant system – we will help you to do this.
Data cleansing and analysis is underway and the next national (and site level) reports will be published in September 2016.

Q. Will there be an IBD Registry report?

A. There will be an annual IBD Registry report, which is expected to be published in June each year, starting June 2017.

Technology

Q. What are the IBD Registry compliant IT systems?

A.
- IBD Registry web tool:
  Similar to the biological therapies audit web tool but can capture a more comprehensive dataset. Is free for use in the first year, contact us for further information: ibdprogramme@rcplondon.ac.uk
- Patient Management System (PMS)
  An IBD Registry designed patient management system that can be integrated with existing hospital systems. Built using Infoflex software and can export the IBD Registry core dataset for analysis and linkage. For further information contact: simone.cort@ibdregistry.org.uk
- EMIS
  An IBD Registry compliant patient management system designed for Gastroenterology. Contact EMIS for further information: https://www.emishealth.com/
- Own hospital's system(s)
  Where IBD teams are unable to use the web tool, PMS or other IBD Registry compliant system, existing hospital systems can be developed or adapted to become IBD Registry compliant. An IBD Registry data submission framework document explains which data items and extract facilities have to be built into any locally

designed database. You can download this here: http://ibdregistry.org.uk/data-submission-framework/

Q. Will I lose the data I have already entered into the biological therapies audit web tool when I move to the IBD registry?

A. No. You can export all of your raw data from the biological therapies audit web tool, at any time. We are also developing a specific 'IBD Registry export' which will exactly match the data fields within the IBD registry.

IBD Registry web tool users - an import function is being built within the IBD Registry web tool which can be used for direct transfer
PMS users – the above import should be compliant with the PMS, or at least require very little adaptation. Please liaise with your local superuser, or CIMS for guidance on this
Users of all other systems – please liaise with your system developer(s) to explore how they can enable you to make use of the specific IBD Registry export that is being developed

Q. We have plans to use the PMS but are not sure when this will happen, what should we do in the meantime?

A. Use the IBD Registry web tool in the interim. All data collected in the web tool can be transferred to the PMS when you are ready to begin using it. At present we understand that this will be done without additional cost but this will need to be confirmed with the supplier as part of your contract with them.

Governance

Q. Do I need to obtain consent to enter data to the IBD registry?

A. Patient consent is not needed to record data on the web tool but it is in principle needed in order to submit data to the IBD registry. At present the IBD Registry has an exemption certificate (called S251); this means that data can be submitted unless patients formally chose to opt out. This exemption is due to expire in May 2016 but an extension is being sought.
The S251 applies to hospitals in England and Wales, exemption arrangements are not yet in place in Northern Ireland orScotland, so consent would be needed to submit data to the IBD registry.

Q What do you mean by 'submitting data to the IBD registry'?

A Submitting data to the registry is the point at which you chose to upload your data for central analysis and/or linkage – essentially secondary use. For example, in England and Wales the data is submitted to the IBD Registry by uploading it to the Health and Social Care Information Centre (HSCIC). You can record the data without choosing to submit it to the IBD Registry but you would not be able to benefit from the linkage to other centrally held datasets or national analyses.

Q. Is the IBD Registry web tool different to the biological therapies audit web tool?

A. Yes. While the IBD Registry web tool captures the vast majority of the data covered in the biological therapies audit, it also offers the opportunity to capture information about the whole IBD patient pathway (eg clinic, admission, medication information). It is not limited to patients being treated with biological therapy.

Q. **Does it make any difference which country my hospital is in?**

A. Not at the moment. For now, you should register with us and continue to collect data through your existing system (e.g. the biological therapies audit web tool). There may be slightly different governance arrangements in each of the home nations, but these will all be explained to you in your starter pack.
If you work in Scotland, we would encourage you to come along to the IBD Registry workshop later this year – you can register here: http://ibdregistry.org.uk/workshops/

Q. **What will my IT department need to do to set up the IBD Registry web tool,?**

A. They will need to make a change to the hospital firewall which will enable access to the IBD Registry web tool through the N3 network and they will need to install an encryption certificate on the hospital server. This is a simple process and the starter pack will contain more detailed information for your IT department.

Quality accounts (QA) and national clinical audit and patient outcomes programme (NCAPOP)

Q. **Is the IBD programme on the quality accounts (QA) list?**

A. Yes. Up-to-date information about the QA list for 2016-2017 can be found here: http://www.hqip.org.uk/national-programmes/quality-accounts/. An earlier, incorrect record has since been amended by HQIP. The IBD programme is a part of the NCAPOP list and on the QA list this year.

Q. **What do we need to do to satisfy our QA reporting?**

A. Please refer to the FAQ titled '**What data should I capture initially?**', in the 'Getting started' section of these FAQs

Do you have a question that isn't covered here?

Contact us.

Any queries please contact the IBD programme team at ibdprogramme@rcplondon.ac.uk or call 020 3075 1521